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ABSTRACT

A survey of personal freedom completed by 97 mothers of handicapped children touched on such aspects as amount of time spent away from the home, arrangements for supervision of the child, and views regarding women's liberation. Data analysis pointed up such findings as a lack of correlation between the child's age and the mother's working hours, but a highly significant positive correlation with the amount of time away from home devoted to the mother's education (significantly reserved for evenings). In addition, a significant number of mothers had either full or part time jobs or were involved in volunteer activities outside the home. (CL)

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Because of the current controversey over the Equal Rights Amendment and the movement for human liberation, people are becoming more aware of the personal rights and freedoms of mothers. It is certainly time to take a look at where we are in regard to our child raising practices. Working mothers are not new to America, but what is new is the number of mothers who work. According to the Women's Division of the Bureau of Labor Statistics, employment of women is on the rise.

From 1940 to 1972, women in the labor force more than doubled from 13.8 million to 32.9 million. That is not so surprising as we all have noticed that more women are working than ever before. But while it is merely doubled for women in general - for working mothers the future has increased more than eight fold, from 1.5 million in 1940 to 12.7 million in 1972. As a matter of fact, in March 1972, 12.7 million mothers with children under 18 were working or seeking work, and, of these, 4.4 million or 1 out of 3, had children under the age of 6. In 1974, more than 1/2 of all mothers with children 6-17 years old were working. In addition, one out of 10 women working was the head of a family.

Projections for 1985 indicate 6.6 million mothers with children under the age of 5 will be in the labor force. These projections were made by the Bureau of Labor Statistics, the Department of Health, Education and Welfaer, the Department of Commerce, and the Bureau of Census. The projections were based on such things as: population mobility (rural to urban), and the accompanying dynamics, the increase in the divorce rate, and economic situation. Actually, there are more mothers working who have children under 18 than who have children over 18. Women's rising awareness of their needs for personal growth as stimulated by the women's movement must be a contributor to the changing role of women in general and of mothers in particular.

How does this apply to mothers of handicapped children? The extraordinary parenting demands on the mothers of handicapped children are well known. As Leo Buscaglia said in The Disabled and Their Parents, "A parent is always a person first, having a child is merely one part of a complicated role as a person. The parent is also a daughter or son, wife or a husband, citizen, consumer and many things." Are mothers of handicapped children included in the increased number of working mothers, or have the special burdens and responsibilities of caring for disabled children kept their role relatively unchanged. With the help of Fern Frank, principal of Julia Malloy Education Center in Morton Grove, we did a quick check of the number of mothers who gave a telephone number at work, to be called in case of an emergency; and we were surprised to learn that 50 out of 113 or 43% of the mothers were working! By the age of the handicapped child, the percentage of mothers working was:

3-5 year olds, 13%
6-10 years, 41%
11-15 years, 53%
15-21 years, 65%

While this was a very small sample, and the percentage was somewhat below national average, we realized that indeed a very substantial number of mothers of mentally handicapped children were not "parenting" in the traditional way.

In attempting to research the issue, we found that little is known about the topic. Apparently, very few people are interested in understanding or in helping out the mother of the mentally-handicapped child to function as other women in the area of personal freedom. Most of the serious research has been done in the area of parents behavior toward and feelings for the retarded child and the relationship between husband and wife.

Farber, in 1959, found that religious affiliation and support from

the wife's mother were important factors in highly integrated marriages in which one child was retarded. Disturbing influences upon the marriage were high participation by the wife's mother-in-law and a high degree of "neighborliness" with mothers on non-handicapped children. Husbands who were active in parent groups were found to be in less stable marriages than those inactive fathers.

Donnelly, in 1960, found that mothers and fathers differ significantly in their behavior toward emotionally disturbed children. The most useful finding was the greater objectivity of the father's behavior, while the emotionality colors the mother-child relationship. Mothers tended to over-baby and were very anxious about their special children.

Boles, in 1960, studied the mothers of Cerebral Palsied Children and found them to be over protective and maritally conflicted. Mothers of older children were more guilty, rejecting, and unrealistic than mothers of younger children. Mothers of younger children were more socially withdrawn. Catholic mothers were found to be the most guilty and hold the more unrealistic expectations for their child. Jewish mothers provided more social opportunities for their children. Protestant mothers of both younger and older children were found to be significantly less anxious and less socially withdrawn than the Catholic and Jewish mothers combined. Interestingly, Farber also found that while among non-Catholics, parents with a retarded son at home were more disturbed in their marital relationship than those with their child in an institution, there was not a difference in Catholic marriages.

The issue of personal freedom and the right to self-esteem and job satisfaction for these mothers had been overlooked. Ms. Baer and myself did a preliminary survey of the needs of mothers of handicapped children. We elicited the cooperation of three special education

principals in the north suburban Chicago area. We sent surveys to 220 mothers of handicapped children, 97 of which were returned. We tried to assess how these mothers managed to pursue their personal interests and activities inside or outside of the home.

What were some of the issues which we addressed in our survey? Of the mothers who returned the survey, fifty-six percent were away from the home for specific hours on a regular basis. Forty-five percent of those women were working. The largest group were in office jobs (14%) followed by professional women (12%), and those who considered themselves "paraprofessional" (10%). Most of the working mothers (40%), were gone Monday through Friday.

Fifteen percent of the women regularly away were attending school, ten percent of which were doing college level work. Most (18%) attended school in the evenings. Thirteen percent of the mothers regularly away for specific hours were doing volunteer work, during school hours or in the evenings.

Ninety-five percent of the mothers who answered saw their children as handicapped. The children ranged in age from three to twenty. The two largest groups had children at age three to four (10%) and age fourteen (13%). Fifty-three percent of the children were male. The breakdown as to nature of the handicapping condition was as follows:

| Nature of Handicapping Condition | Percent of Students |
|---|---|
| Downs Syndrome | 29% |
| Physical (only) | 4% |
| Emotional | 2% |
| Severe Multiple Handicap | 9% |
| Speech | 4% |
| Both Physical and Developmental | 5% |
| Cerebral Palsy (only) | 11% |
| Other Developmental (only) | 32% |
| Other | 4% |

How did the mothers see the severity of their child's disability? Most mothers (55%) saw their child as moderately handicapped. Twenty-two

percent saw them as mildly handicapped and twenty-one percent saw them as severely handicapped! How the child was cared for during the time during which mother was away is as follows:

| Who Watches the Child | Percent |
|---|---|
| Grandmother | 5 |
| Father | 12 |
| Other Family Member | 19 |
| Supervised Public Private Program | 19 |
| Paid Sitter (other than family member) | 10 |
| Child Stays Alone | 7 |
| No answer or not applicable | 28 |

It would seem that while a large number of mothers have coped with the issue, a good portion (28%) have no solution, except their own dillegence! We were interested in the "left alone" group of children, so we asked how old he/she was when first left alone. The age range was from eight to nineteen, with the group starting at age twelve (6%) seeming to be the most typical. Fourteen percent had a systematic method of teaching their child to take care of himself, and several shared their methods with us. It took some mothers (2%) less than a week to teach their child this skill and others (5%) over a year to teach them to care for themselves until mother returned. Forty-nine percent were satisfied with the child care arrangement which they had made. Others felt that they needed more permanence in the sitting arrangements or that the child would bother others, or could put himself in a dangerous situation. Only five percent felt that their outside activities had had a negative effect on their handicapped child. Most felt that it had had no effect, and several thought the effect was positive (e.g., making the child less dependent on the mother). If their child weren't handicapped, most mothers felt that he/she would have probably spent his/her time after school with peers (34%)

The survey addressed the quality and cost of school and other supervised programs as day care facilities for working mothers. Fifty-

five percent were in public school programs in our study, and most students went to school and back by school bus. What happened to the child if he was ill, or if school was closed because of a holiday? Twenty-four percent of the mothers would also stay home then. Other options used were father or friend or relative stayed home, the child stayed alone or at a friend's house, or a paid sitter was hired. Forty-two percent of the mothers could be home within a half hour of an emergency call, but only forty-one percent felt that they could be contacted during working hours!

Only two percent of their employers were not aware that they had a handicapped child, but twenty-three percent felt that their choice of job and the hours which they worked hadn't been influenced by their child. Sixty-eight percent felt that their child could generally follow instructions, yet forty-four percent weren't sure if their child could take care of himself in case of an emergency! Forty-four percent were familiar with the Women's Liberation Movement, and the same percent knew about the Council on Exceptional Children. However, only eight and six percent, respectively, felt that these movements had had any influence or impact on themselves or their families. Eighty-eight percent of the mothers were currently married, eighty-four percent had other children, and their age ranges were:

| Range | Percent |
|---|---|
| Under 25 | 1 |
| 26-32 | 13 |
| 33-40 | 30 |
| 41-50 | 37 |
| 50 and over | 18 |
| No answer | 1 |

With our limited collection of data, we tried to find some significant correlations between pertinent issues which we saw arising from the survey. We found that the age of the child did not correlate with the

hours that the mother worked, but that there was a highly sifnificant, positive correlation with the hours that mothers spent away for their own education. Educational activity was significantly reserved for evenings. The nature of the handicap was not correlated with the sex of the child. There was a highly significant, low negative correlation between the age at which the child was left on his own with the mother's perception of the severity of his disability. The age at which the child was first left on his own was not correlated with the age of the mother. There was a highly significant, positive correlation between the age at which the children were first left on their own and the nature of the handicapping condition. A significant number were away from home for volunteer and other activities, even if they didn't work or go to school, but being away from home regularly was not correlated with the sex of the child. A significant number were involved in a job either part time or full time, as well as volunteer activities outside the home.

How did the mothers in our survey feel about the issues which were raised? There seemed to be an overwhelming sense of gratitude that "somebody" cared about their personal freedom, or lack of it. Perhaps the best way for conveying the feeling is with some of their own words:

"My handicapped son is almost ten years old and never before has anyone asked how a family manages. This is a welcome survey to me. I think the results should be published as I am very interest in how other families manage. I often ask them, and, unless they are very close friends, they will say the handicapped child is no different to care for than the normal children. I just don't buy this. To my husband and myself, there is a <u>vast</u> difference and people on the outside just don't realize. They will ask me to play bridge one night a week, go to Sunday afternoon concerts, etc. I cut out as many extra activities as

possible and my husband does the same so that we don't burden the other with too much 'babysitting.'

Our child is particular about who takes care of him, so it is difficult to find a person who can handle him properly and also keep him contented."

"I feel this survey struck upon very good issues, unfortunately, it was one that was long overdue. However, it is, of course, never too late.

I have been working since my youngest has been 3 years old and it has been only a constant struggle, a lot of mental anguish and financial difficulty. The reason being, I had so many different baby sitters (some good, some ba I remember on year, especially, I had paid over $1100 in daytime sitters alone.

I would enjoy being active in organizations, having activities that I would be interested in, however, due to the time taken up with a handicapped child, holding down a job, etc., (I also try to help out with school projects), I feel like I'm spreading myself too thin.

I do not believe a great deal in Women's Lib, but my advise and hope for other working mothers is to somehow get fathers to give more of a helping hand either physically, or helping to get a sitter and sharing the burden more.

If the mother is widowed or divorced, I hope and pray that the government will subsidize the mother/parents before the child reaches the age of 18. Today, people and organizations are helping children and parents to cope. I hope it is the beginning."

"As working mother, I have learned to leave my child alone out of necessity - sitters became an insurmountable problem, especially

as she got older. It is not the best solution because of her limitations - she can be trusted not to use the stove, but she forgets always and opens the front door to anyone who knocks, forgetting sometimes to be fully dressed. She is happy with our arrangement, however, and it will continue.

Going out at night is another problem - my anxieties have, until these last few months, made me dependent on my son to stay with her on the occasions that I needed to go out on a Saturday night. This, of course, became increasingly unfair to him, so slowly, I started to leave her alone, first for only an hour and then a little longer. When I was able to put her to sleep first, I had it made, but that couldn't always be, so I've made the bread - she can even put herself to bed now, but nights are hard! Another major problem is spring vacation or the like. Three days can be filled easily, leaving two to flounder. Often one free day is problematic, a whole day alone is out of the question. What we need are some educated senior citizens who could come to us.... It would be a wonderful experience for child and adult."

We would like to continue to research the needs of the mothers of handicapped children. We believe that we have found an area wanting in solid research. I realize that what I have done so far is merely a "fishing expedition" into the topic, and that further study is needed. During the C.E.C. Convention, I met with Mr. Max Mueller of the Bureau of Education for the Handicapped and discussed research implications in this area. He felt that his department might be able to eventually fund such research, or that he would support my contact with Dr. Edith Grotberg of the Office of Child Development.

Certainly several areas could be developed as a result of this research. Counseling techniques could be improved by a better under-

standing of the issues of new or young mothers in relation to the area of personal freedom. The need for day-care facilities might be implied as well as the need for better after school community programs for handicapped children. This study could make a contribution in the areas of advocacy and normalization for the mentally handicapped. There are implications for curriculum planning in special education. A large percentage of these children are left alone at home. Can they take proper care of themselves? Should this be a curricular issue? We hope to find the answers.

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February, 1976

# VITA

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| 9/75 - present | Assistant Professor of Psychology<br>Rehabilitation Counseling Program<br>Supervisors: Dr. David B Hershenson<br>Dr. Glen O. Geist | Illinois Institute of Technology<br>Life Sciences Bldg.<br>Chicago, IL 60616 |
| 11/75 - present | Coordinator of Field Experiences<br>Rehabilitation Counseling Program<br>Supervisor: Dr. Glen O. Geist | Illinois Institute of Technology<br>Life Sciences Bldg.<br>Chicago, IL 60616 |
| 1/74 - 8/75 | Human Development Counselor<br>Supervisors: Dr. Jane Allen<br>Mr. Lloyd Lehman | Regional Service Agency<br>7700 Gross Point Rd.<br>Skokie, IL 60076 |
| 9/72 - 2/74 | Director of Career Counseling and Placement, and Foreign Student Advisor<br>Supervisor: Dr. Gloria Lewis | Mundelein College<br>6363 N. Sheridan Rd.<br>Chicago, IL 60626 |
| 6/67 - 3/70 | Science Teacher<br>Supervisor: Eldon Carper | Northbrook Jr. High<br>1475 Maple<br>Northbrook, IL 60062 |

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| | | |
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| 6/75 - 8/75 | Teacher<br>Theories of Counseling<br>Supervisor: Dr. Joseph Rizzo | Barat College<br>Lake Forest, IL 60034 |
| 3/73 - 12/75 | Teacher-Career Counseling<br>Supervisor: Mr. Orlando Ponzio | Wright Junior College<br>3400 N. Austin Ave.<br>Chicago, IL |
| 6/73 - 9/74 | Counselor<br>(Mundelein) Counseling Center for Women<br>Supervisor: Dr. Frank Miller | Mundelein College<br>6363 N. Sheridan Rd.<br>Chicago, IL 60626 |

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CERTIFICATION, HONORS, AWARDS:

State of Illinois Certificates in School Service Personnel: Guidance and Counseling; High School 6 to 12; Counseling Psychologist (applied for); Certified Rehabilitation Counselor (applied for).

Teaching Assistantship at Northwestern 6/73 to 6/74 - duties included supervision of Master's student, teaching introductory courses, and supervising vocational testing for students in the School of Education.

Illinois State Scholarship (Honorary) 1964 to 1967.

Member of Circumference (Women's Honor Society) at Loyola 6/66 to 6/67.

Officer KBG Sorority 9/66 to 6/67, National Recording Secretary 1970-72, Chicago Alumnae President 1975-76.

PUBLICATIONS: ICEC Journal, Summer 1975, "Sex Education for the Mentally Handicapped - the First Year:

PANELS: NAWDC, Cleveland, Ohio, April 1973, "Confessions of Former Sexists"

IGPA, Chicago, IL, October, 1973, "Concerns of Graduate Students in Counseling"

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PAPERS: Northwestern University School of Education Summer Conference, June, 1974, "Adolescents Attitudes Toward Sexuality"

IGPA, Chicago, IL, October, 1975, "Counseling the Special Education Student about Sexuality"

CEC, Chicago, IL, April, 1976, "The Influence of the Women's Movement on the Mothers of Mentally Handicapped Children: The issue of Personal Freedom" - filed with ERIC

DISSERTATION TITLE: The Effects of a Program of Sex Education on the Attitudes of Junior High School Students and Their Parents.
Major Advisor: Dr. Frank Miller, Northwestern University

CITATION.- Nov., 1974, Sex Education and Information Council of the United States Bulletin Awards Contest

Included in the lending library of the Institute for Sex Education and Research of the University of Indiana (formerly The Kinsey Institute).

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American Personnel and Guidance Association
American Psychological Association (applied for)
American Association of Sex Educators and Counselors
Council of Rehabilitation Counselor Educators
National Rehabilitation Association
National Rehabilitation Counseling Association
National Vocational Guidance Association
Illinois Association of Women Deans and Counselors
Illinois Guidance and Personnel Association - Publicity Chairperson, 1976
Illinois Psychological Association
Illinois Rehabilitation Associations
Illinois Rehabilitation Counseling Association - Chairperson, Scholarship Committee, 1976

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